THE NOONAN SYNDROME SUPPORT GROUP, Inc.
A NON-PROFIT SUPPORT GROUP

Hello and Welcome,

Thank you for showing interest in the Noonan Syndrome Support Group. The enclosed package of information has been obtained from an array of different sources, and it is our hope that many of your initial questions will be answered after reviewing the material.

This information package can seem overwhelming. We, as NS parents, have found that it is easier to handle each of the anomalies associated with NS as they present in our children. In other words, we concentrate on the information that relates to our children at a given time. As one doctor said, "What you see today will change a lot as the years go by."

Members of TNSSG include: people with NS, family members, friends, and Medical Professionals. We come from all walks of life—representing a host of ethnic groups. We are from different areas of the United States, Europe, Canada and even as far away as South Africa! The common ground of the membership is our desire to stay informed about Noonan Syndrome and to share information, ideas, and concerns.

The Group also operates an Internet list service. As of November 1998 there are 114 subscribers on the list. Please join us and subscribe to the list, it's free! To subscribe, send an e-mail to: **listserv@home.ease.lsoft.com** with the command **"SUBSCRIBE NOONAN-SYNDROME"** in the body of the message. After subscribing, you will immediately be able to send messages to the list and receive messages from the list.

The Noonan Syndrome Support Group, Inc. gratefully accepts contributions as the group is non-profit and self-funded. Without your contribution, we might not be here for the next family.

Please let us know if you would like any additional information.

Sincerely,

Wanda

Wanda Robinson

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The Noonan Syndrome Support Group INC. Offers:

- **Consultation** - Members can get useful information to their questions on issues such as insurance and medical care.

- **Resource Center** - Members have access to the most recent articles published.

- **Newsletter** - <u>The Noonan Connection</u> is published on a quarterly basis. It includes articles addressing current issues related to Noonan Syndrome as well as letters from those whose lives have been touched by Noonan Syndrome.

- **Advocacy** - The Group helps by providing accurate information to schools and the Medical Community.

- **Public Relations** - The Group promotes positive attitudes about Noonan Syndrome and awareness among the professional community through the use of public service announcements on television and radio.

- **Support Groups** - Members can share experiences and exchange ideas on how to cope with Noonan Syndrome. Parents with a recently diagnosed child can gain reassurance by meeting with other parents and individuals with Noonan Syndrome.

- **Education** - TNSSG facilitates meetings at which physicians and other professionals have provided useful information on living with the day-to-day challenges of Noonan Syndrome.